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## Can outbreak research be achieved in a population with impaired capacity? Findings from a study of a scabies outbreak in residential care

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### Abstract

**Background** Disease outbreaks in residential care where dementia is prevalent are an important public health concern and challenging to study. To explore the feasibility of outbreak research in a population lacking mental capacity we studied scabies outbreaks in residential care homes for elderly people.

**Methods** Between Jan 23, 2014, and April 23, 2015, participants were recruited from ten residential care homes in South East England reporting scabies outbreaks to their local health protection unit. Preliminary visits were organised in advance of clinical visits to assess mental capacity and, when appropriate, seek consent from residents to be recruited and clinically examined. When residents did not have the capacity to consent, advice was sought from a personal consultee (usually next of kin) via telephone and followed up with written confirmation. When a personal consultee could not be contacted or did not exist, advice was sought from a nominated consultee (institution staff). Researchers were trained to assess mental capacity and did so at each visit because capacity often fluctuates in this population. During two clinical visits, residents were fully examined and skin conditions recorded and photographed. When scabies was diagnosed, skin scrapes and blood samples were taken for analysis and stored for future research. The study was approved by Camberwell St Giles NRES Committee (12/LO/0001).

**Findings** Of 295 residents approached, 144 (49%) were assessed as having capacity to consent and 122 (41%) gave written consent; consultee advice was sought for 151 (51%). All 24 nominated consultees and 117 (92%) of 127 personal consultees advised that they thought the person without capacity would wish to take part. Consent or positive advice was obtained from 264 (89%) of 295 residents for clinical examinations and skin scrapes and from 187 (71%) of 264 residents for photography of skin conditions. Separate consent for storage of tissue and blood samples was introduced partway through and consent or positive advice was obtained for 100 (66%) of 151 residents. 231 (88%) of 264 residents were examined: 155 (67%) had dementia, of whom 54 (35%)

were able to give written consent, and differences in the perceived and assessed capacity between care home staff and researchers were noted. 191 (83%) of the 231 participants were examined at both clinical visits. Reasons why 40 residents were not examined at the 6 week follow-up visit included: deceased (13, 33%), respite or re-enablement (10, 25%), unwell or distressed (7, 18%), admission to hospital (5, 13%), unable to schedule appointment (3, 8%), and refused (2, 5%). 12 (6%) of 191 participants experienced fluctuating mental capacity. Clinical visits took place within a median 5 days (IQR 3–8) of notification of the outbreak to the study team.

**Interpretation** Public health research during outbreaks in residential care is complex but achievable. It requires substantial resource and training to deliver rapid and repeated assessment of mental capacity and obtain timely consultee advice in line with the Mental Capacity Act 2005.

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### **Contributors**

SL, MGH, KH, AN, SLW, and JAC designed the study. JB provided ethics advice. SL, JM, AN, and SLW were involved in recruitment and data collection. SL and JM were involved in data analysis.

### **Declaration of interests**

JB is a member of the National Health Service Research Ethics Committee that reviewed the scabies study. However, she did not review the scabies study nor did she attend the meetings where the study was discussed. She became involved with the scabies study after ethics approval was granted in 2012. The decision to involve her in the scabies study was not influenced in any way by her role within the ethics committee.

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